

You Are Not Alone



Interstitial Cystitis – Bladder Pain Syndrome (IC/BPS) Medical Records File

**Plan Your Appointments - Record Your Test Results
Manage Your Treatments - Track Your Progress
Record A Voiding & Pain Diary - Create Your Support Team
Prepare For Emergencies**

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ICN Medical Records File

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from the publisher

It's very rare for an IC patient to be diagnosed and treated by the first physician they see. Most patients will see several physicians and have a variety of tests before they receive a diagnosis and find someone who can help. Throw in dozens of prescriptions for antibiotics, pain medications, various therapies and other suggestions, it's easy to become overwhelmed with information, much less remember what you've taken and why.

You, the IC patient, must keep track of your medical care. You need to know what tests you've had, when they occurred and the results. You should know exactly what they are putting in your bladder and/or why. You should track the therapies you've tried, how long you used them or why you stopped them. Most of all, you need to record your progress.

I've developed this medical file to help you review and discuss your medical care with your various physicians and medical professionals. It is composed of eight sections and should be placed in a binder or notebook so that you can add additional pages, as needed.

- The Medical Care Directory
- The IC Diagnostic Testing History
- The IC Treatment History
- Pelvic Floor Therapy Log
- The IC Support Directory
- The Emergency Care Instructions
- The Voiding & Pain Diary
- The Physician Appointment Log

Successful IC patients are those who are active and equal partners in their medical care. Your efforts, or lack thereof, will strongly contribute to your success. By keeping these basic records, you will make better decisions about therapies, particularly when faced with stopping a medication that could be working for you. Furthermore, if you do struggle with pain, this file will help you create supporting evidence that can help justify your need for pain medication and care. It is well worth the effort. Good luck!

- Jill Osborne, ICN Founder

Medical Care Directory

Take a moment and record your insurance and medical care provider information here. You'll notice that we also ask you to record the names of the receptionist and nurses involved with your care. Often, nursing staff is our lifeline. They usually handle phone requests and can provide assistance during flares. We strongly recommend that you get to know them on a first name basis. Always remember that you deserve the best care available, particularly physicians who are knowledgeable about IC and compassionate to their patients.

Name: _____ Phone: _____
Address: _____ Cell Phone: _____
City, State, Zip: _____ E-mail: _____

Health Insurance Company: _____
Insur. ID #: _____
Address: _____
City, State, Zip: _____
Phone: _____ Website: _____

Medicare Insurance ID#: _____
Address: _____
City, State, Zip: _____
Phone: _____ Website: _____

Pharmacy: _____ Phone #: _____

My Urologist

Doctors Name: _____
Office Name: _____
Office Address: _____ City, State: _____
Daytime Phone: _____ Emergency Phone: _____
E-mail: _____ S/he has been my doctor since: _____
Nurse & Receptionist Names: _____

My Primary Care or Family Doctor

Doctors Name: _____
Office Name: _____
Office Address: _____ City, State: _____
Daytime Phone: _____ Emergency Phone: _____
E-mail: _____ S/he has been my doctor since: _____
Nurse & Receptionist Names: _____

My Gynecologist (for females)

Doctors Name: _____
Office Name: _____
Office Address: _____ City, State: _____
Daytime Phone: _____ Emergency Phone: _____
E-mail: _____ S/he has been my doctor since: _____
Nurse & Receptionist Names: _____

My Physical Therapist (for pelvic floor therapy)

Therapist's Name: _____
Office Name: _____
Office Address: _____ City, State: _____
Daytime Phone: _____ Emergency Phone: _____
E-mail: _____ S/he has been my doctor since: _____
Nurse & Receptionist Names: _____

Other Medical Professionals

Name: _____
Specialty: _____
Office Name: _____
Office Address: _____ City, State: _____
Daytime Phone: _____ Emergency Phone: _____
E-mail: _____ S/he has been my doctor since: _____
Nurse & Receptionist Names: _____

Name: _____
Specialty: _____
Office Name: _____
Office Address: _____ City, State: _____
Daytime Phone: _____ Emergency Phone: _____
E-mail: _____ S/he has been my doctor since: _____
Nurse & Receptionist Names: _____

Doctors I No Longer See

Name: _____
Office Address: _____
City, State: _____
Daytime Phone: _____
Dates seen: _____
Reason for stop? _____

Name: _____
Office Address: _____
City, State: _____
Daytime Phone: _____
Dates seen: _____
Reason for stop? _____

Doctors Name: _____
Office Address: _____
City, State: _____
Daytime Phone: _____
Dates seen: _____
Reason for stop? _____

Doctors Name: _____
Office Address: _____
City, State: _____
Daytime Phone: _____
Dates seen: _____
Reason for stop? _____

Diagnostic & Testing History

Testing can be expensive and uncomfortable. Rather than risk having to have a procedure again, keep track of the tests you've had here. Whenever possible, get written copies of test results and if you're having a hydrodistention with cystoscopy, ask for a videotape and/or pictures of your procedure. If you are struggling with recurrent urinary tract infections in addition to your IC, please record the type of infection you have. Is it an E-Coli infection? Staph? Enterococcus? If you don't know, ask for the information and also for antibiotic sensitivity testing to determine which medication will kill your specific infection.

I first had bladder symptoms in what year? _____

My initial symptoms were: _____

Date of Diagnosis: _____ **By?** _____

I have had the following tests:

(Please list all urology tests, urine cultures, radiological procedures, pelvic floor assessments, etc.)

Name of test: _____ Date: _____

Who requested the test or procedure? _____

Why was it requested? _____

Who performed the test? _____

Where was it performed? _____

Results: _____

Name of test: _____ Date: _____

Who requested the test or procedure? _____

Why was it requested? _____

Who performed the test? _____

Where was it performed? _____

Results: _____

Name of test: _____ Date: _____

Who requested the test or procedure? _____

Why was it requested? _____

Who performed the test? _____

Where was it performed? _____

Results: _____

Name of test: _____ Date: _____

Who requested the test or procedure? _____

Why was it requested? _____

Who performed the test? _____

Where was it performed? _____

Results: _____

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Where was it performed? _____
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Where was it performed? _____
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Who requested the test or procedure? _____
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Who performed the test? _____
Where was it performed? _____
Results: _____

Name of test: _____ Date: _____
Who requested the test or procedure? _____
Why was it requested? _____
Who performed the test? _____
Where was it performed? _____
Results: _____

IC Treatment History

One of the most frustrating experiences doctors may face are new patients who can't tell them what therapies they've tried, when they used them and why they may have stopped. Record all of your therapies here and add additional pages as needed!

Name of Treatment: _____
How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

Name of Treatment: _____
How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

Name of Treatment: _____
How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

Name of Treatment: _____
How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

Name of Treatment: _____
How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

Name of Treatment: _____
How is it supposed to help? _____
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Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

Name of Treatment: _____
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Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

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How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

Name of Treatment: _____
How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____
Doctors Name: _____
Date Prescribed: _____ Date Ended: _____ Duration of Treatment? _____
Specific Results? _____
Why did you stop this treatment? _____
Did you experience any side effects? _____

Pelvic Floor Therapy Log

IC patients often have an underlying pelvic floor muscle dysfunction, usually extremely tight, painful muscles in the pelvis that contribute to IC flares and pelvic pain. Indeed, one reason why intimacy can be so difficult for patients is due to the pelvic floor tension and/or the spasms that can occur during and after intercourse. Another classic symptom of tight pelvic floor muscles is difficulty starting your urine stream or needing to strain to urinate. Riding in a car can often trigger pelvic floor spasms. Thus, more and more urology clinics now provide a pelvic floor assessment as part of the diagnostic process as well as access to physical therapy if pelvic floor dysfunction is found.

Pelvic floor rehabilitation takes time and effort, especially if you've had long-term symptoms. A physical therapist can manually and gently massage the muscles to help them release tension as well as use various machines to teach you how to relax those muscles. These appointments may occur weekly. They may also train a spouse or partner how to help. Of equal importance is having a daily management program at home to "teach" your body how to be relaxed. This can involve using relaxation & anxiety management tapes, as well as gentle exercises provided by the therapist. To treat the bladder without treating the pelvic floor muscles can waste valuable time.

Have you had a pelvic floor assessment? Yes or No

Who performed the exam? _____

What were the results of the exam? _____

Were any trigger points found? If so, where? _____

What type of therapy was suggested, if any? _____

Name of physical therapist? _____

After first visit, please describe their treatment plan? What therapy do they propose? _____

How many visits are expected? _____

How often should they occur? _____

Home exercise #1: Please describe what they would like you to do? _____

How many times should you do them each day? _____

How many repetitions should be done? _____

Home exercise #2: Please describe what they would like you to do? _____

How many times should you do them each day? _____

How many repetitions should be done? _____

Home exercise #3: Please describe what they would like you to do? _____

How many times should you do them each day? _____

How many repetitions should be done? _____

Support Directory

There's no doubt that IC can be isolating and create loneliness. IC patients have often made the mistake of trying to explain their symptoms and frustrations over and over to spouses, family members and friends only to receive the dreaded "blank stare." Truly, it takes another patient to understand what another IC patient is going through. Not only can we sincerely relate to what you are going through, we may also have tips and suggestions that can help. There are two options for support: local "in person" support groups and support on the web. The IC Network offers 24-hour support in our support forum and monthly live chats. You can also find a list of local support groups in the USA, as well as other international patient organizations on our website. (<http://www.ic-network.com>).

My Local Support Group Leader(s)

Name: _____
Address: _____ City, State: _____
Daytime Phone: _____ Night Phone: _____
E-mail: _____ ICN Name: _____ Facebook Name: _____

Name: _____
Address: _____ City, State: _____
Daytime Phone: _____ Night Phone: _____
E-mail: _____ ICN Name: _____ Facebook Name: _____

My Personal IC Buddies

Name: _____
Address: _____ City, State: _____
Daytime Phone: _____ Night Phone: _____
E-mail: _____ ICN Name: _____ Facebook Name: _____

Name: _____
Address: _____ City, State: _____
Daytime Phone: _____ Night Phone: _____
E-mail: _____ ICN Name: _____ Facebook Name: _____

Name: _____
Address: _____ City, State: _____
Daytime Phone: _____ Night Phone: _____
E-mail: _____ ICN Name: _____ Facebook Name: _____

Name: _____
Address: _____ City, State: _____
Daytime Phone: _____ Night Phone: _____
E-mail: _____ ICN Name: _____ Facebook Name: _____

Name: _____
Address: _____ City, State: _____
Daytime Phone: _____ Night Phone: _____
E-mail: _____ ICN Name: _____ Facebook Name: _____

Emergency Care Instructions

Please make a photocopy of this page and place it in your wallet and car. You can also give copies to your family members who are your trusted emergency contacts. Having someone who can speak for you should an accident happen is vital.

My Name: _____ Home Phone: _____ Cell Phone: _____
Address: _____
City, State, Zip: _____ Email: _____

My Health Insurance

Company #1: _____ Insur. ID #: _____
Company #2: _____ Insur. ID #: _____

Emergency Contacts

#1. Name: _____ Phone: _____
Relationship: _____ Email: _____

#2 Name: _____ Phone: _____
Relationship: _____ Email: _____

My Medical Care Team

Urologist: _____ Phone: _____
Primary Care: _____ Phone: _____
Gynecologist: _____ Phone: _____
Pain Specialist: _____ Phone: _____

Medications

I am on the following medications: _____

I am allergic to the following medications: _____

Instructions

If you require Emergency Medical Care, what specific instructions would you like your representative to communicate to hospital or emergency personnel?

Voiding & Pain Diary

A voiding and pain diary will allow you to communicate clearly with your physician about the status of your bladder and track the progress of various IC treatments. Some IC patients stop treatments prematurely. A subtle decrease in frequency is one sign that a treatment is working. Yet, if you aren't keeping a record of your frequency, you may not see this progress and stop what could be a successful treatment for you. Remember, your memory is not good enough. It does not help for you to visit the doctor and say "I'm not any better." You need to be able to back that up with bladder facts, such as: "I'm not feeling any better and I'm now urinating 20 times a day instead of 15 times a day."

What should be recorded? In a small, spiral notepad, label the top of each page with the date and day of the week. For each time you urinate that day, please write down the time and a rough estimate of your volume (i.e. 1 cup, 1/2 cup, 1/4 cup, 1 TBS, 1 drop). Then take a moment and ask yourself what is your pain level at the time of that urination on a scale of 1-10. Be specific if you can and make a note of where the pain is.

How often should I do it? If you're newly diagnosed and tracking your progress, it is helpful for you to do it every day for a 2-3 months to help you learn your normal monthly cycles. Women may flare during ovulation and/or a few days before their period. When you actually see that occurring, you'll be able to say "Oh, that's just my monthly flare." Your voiding diary will also help you track down hidden triggers. After a few months, reduce it to three times a week or perhaps do one week a month. Make sure you save your diaries. They can be copied and given to your doctor for your medical file to serve as evidence of your bladder symptoms. They can be vital evidence in support disability insurance applications.

Sample Diary – Weds., August 2, 2006			
Time of void	Rough Volume	Pain Level (1-10)	Notes
2:30am	1/4 cup	3	Bladder burning
3:15am	1 drop	3	Why did I have that glass of wine at dinner?
4:30am	1/4 cup	3	Pressure & burning
6:00am	1/4 cup	4	Took pain med. Had some water.
8:10am	1 cup	3	Feeling pressure
10:00am	1/2 cup	5	Throbbing – vulvar discomfort – took med.
11:20am	1/2 cup	3	
1:10pm	1 cup	3	
2:15pm	1/4 cup	3	
3:45pm	1/2 cup	2	Better wow!
5:10pm	1 cup	2	Had a good dinner... no IC cheats
6:30pm	1/4 cup	1	
7:30pm	1/4 cup	1	
9:30pm	1/2 cup	1	
11:35pm	1 cup	1	Feeling sleepy. Hope to have a good night
TOTAL		Avg. Pain: 2.7	Voided 15 times

SAMPLE PAIN SCALE

When someone asks you to rate your pain on a scale of 1-10, it can be confusing. Many patients rate their pain at a level 10 inappropriately. Here's a rating scale that might be helpful. As always, talk this over with your physician if you have any questions.

Level 1: I feel no symptoms of IC. I can do anything.

Level 2: I feel slight discomfort, possibly the beginning of a flare. I can do anything.

Level 3: I feel mild symptoms of IC. It is not stopping me from my daily life but I am feeling some mild discomfort.

Level 4: I feel moderate symptoms of IC. I have moderate need to urinate and/or moderate level of pain. I am limiting my activities. My frequency is higher and I'm now looking for restrooms and using them. At this point, I'm on my way home to rest and begin my pain management strategies and/or use pain medication.

Level 5: I'm very uncomfortable, perhaps biting my lip and/or holding my abdomen. I'm usually laying in bed or a recliner now. Walking is more painful now. IC has limited me from doing my daily functions. I am utilizing some of my pain management medications and tools at this point.

Level 6: I'm having constant intense pelvic pain with moderate frequency and urgency. I'm worried and ready to call my doctor for advice.

Level 7: I'm in bed in severe pain. I'm using all of my pain strategies. I may need help at this point.

Level 8: I am having difficulty tolerating the pain. I have called my doctor and may go to emergency room for help.

Level 9: My pain is intolerable. I am on my way to the emergency room or doctors office because I need help in managing my pain.

Level 10: I am in excruciating pain and am at the emergency room or hospital.

Here are some helpful questions to ask yourself that can help you keep an effective pain diary.

- 1 In what area is the pain located? urethra, vaginal area, bladder, right under the belly button, scrotum, penis etc..
- 2 When is the pain worst? Before you urinate? While you urinate? After you are done urinating?
- 3 Is the pain, aching, burning, dull, pounding, pressure, sharp, stabbing, throbbing or tingling?
- 4 Was there noticeable pain when you woke up?
- 5 Did the pain proceed to get worse during the course of day?
- 6 What do you think might of triggered your pain symptoms? (i.e., food, exercise, sex)
- 7 Have you used any pain techniques to help reduce the pain? (i.e., pain medications, heating pad, ice, relaxation)
- 8 What medications are you taking for pain control? Are they prescription or OTC? Do they help in relieving your pain (never, sometimes, always)
- 9 Do you have trouble sleeping because of the pain?
- 10 Do you have trouble eating because of the pain?
- 11 Do you have trouble sitting because of the pain? Where?

Physician Appointment Log

Please complete one log per appointment visit.

Your Name: _____
Physician Name: _____ Specialty: _____
Office Location: _____ Date: _____ Time: _____

Why did you make this appointment? _____

Describe clearly what symptoms are you experiencing? _____

Please list the questions you hope to ask your physician?

What action did your physician recommend? *(Circle all that apply)* Examination –
Referral To Another Provider - Hospitalization - Wait and See? - Lab Tests –
X-Rays - Other Treatments - Nothing

What Lab/X-ray/Tests were suggested? _____

What treatment(s) did your physician recommend?
Name of Treatment: _____
How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____

What follow up actions are needed? _____

When would you doctor like to see you again? _____

Date of your next appointment? _____

Physician Appointment Log

Please complete one log per appointment visit.

Your Name: _____
Physician Name: _____ Specialty: _____
Office Location: _____ Date: _____ Time: _____

Why did you make this appointment? _____

Describe clearly what symptoms are you experiencing? _____

Please list the questions you hope to ask your physician?

What action did your physician recommend? (Circle all that apply) Examination –
Referral To Another Provider - Hospitalization - Wait and See? - Lab Tests –
X-Rays - Other Treatments - Nothing

What Lab/X-ray/Tests were suggested? _____

What treatment(s) did your physician recommend?
Name of Treatment: _____
How is it supposed to help? _____
Recommended Dosage (if applicable): _____
Estimate of time given before you would see any results? _____
Any potential side effects? _____

What follow up actions are needed? _____

When would you doctor like to see you again? _____
Date of your next appointment? _____

Twenty IC Resources! Have you tried them yet?

IC Basic Information

- (1) The IC Survival Guide by Dr. Robert Moldwin
- (2) Ending Female Pain by Isa Herrera PT
- (3) Heal Pelvic Pain by Amy Stein PT
- (4) The ICN Special Report: Managing IC Flares
- (5) The ICN Special Report: Managing Pain

Learning About the IC Diet

- (4) Confident Choices: A Cookbook for IC and OAB by Julie Beyer RD
- (5) Confident Choices: Customizing the IC Diet by Julie Beyer RD
- (6) A Taste of the Good Life: A Cookbook for an IC Diet by Bev Laumann

IC Friendly Beverages

- (7) Knudsen Pear Juice
- (8) Tyler's No Acid Coffee
- (9) Euromild & Puroast Low Acid Coffees
- (10) Pero, Cafix & Kaffree Roma Herbal Coffees

Breakfast Ideas

- (11) Dr. Oetker's Organic Pancake or Biscuit Mix
- (12) Colorado Mountain Pear Jelly
- (13) Colorado Mountain Apple Pie Jelly

Energy Foods For A Busy Day

- (14) Pear Pear & Pear Blueberry Bars
- (15) Larabars (Banana, Cherry & Apple Pie)

Irritable Bowel Syndrome Resources

- (16) First Year: IBS by Heather Van Vorous
- (17) Heathers Tummy Care Acacia Fiber

Alternative Supplements Popular With IC Patients

- (18) Algonot, Cystoprotek, CystaQ, Desert Harvest Aloe
- (19) Prelief

Chair Cushions For Those Days When It Just Hurts To Sit

- (20) IC & Prostate Friendly Chair Cushion



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www.icnsales.com